

Governor's Commission on Mental Retardation

Strategies for Change:
Supporting Community Inclusion for
Persons with Mental Retardation

*Report from the Commission's Public Hearing held
Tuesday, September 24, 1996 at Worcester State College*

Strategies for Change: Supporting Community Inclusion for Persons with Mental Retardation

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

Commission Chair:

Marty Wyngaarden Krauss

Administrator:

Betsy Closs

Commission Members:

Charles Austin

Allen C. Crocker

Martha A. Field

Florence S. Finkel

William Gauthier

Mary McTernan

Robert W. Riedel

Richard E. Vincent

Staff Members:

Pat Knipstein

Barbara Mazzella

Emily Micolonghi

The Governor's Commission on Mental Retardation
Saltonstall Building - Room 1103A
100 Cambridge Street
Boston, MA 02202
(617) 727-0517

Introduction

"The Department of Mental Retardation is composed of people dedicated to creating, in cooperation with others, innovative and genuine opportunities for individuals with mental retardation to participate fully and meaningfully in, and contribute to, their communities as valued members." --Mission Statement of the Massachusetts Department of Mental Retardation

"I sometimes hear that people think inclusion is about saving dollars....Inclusion is about saving lives." --Cynthia Levine, Inclusion Coordinator, Ayer Public Schools

"Successful inclusion involves a profound commitment to and belief in [its] importance....Not only for the individual but for the enrichment of the community as well." --Karen Stevens, Director of Program Innovations, The Consortium

The history of mental retardation services is a history of segregation. For over a century, the prevailing method of helping persons with mental retardation has been through the utilization of programs which separate that person from the community at large. Today, the majority of citizens with mental retardation continue to receive services in segregated settings, yet the philosophy of service delivery has undergone a profound transformation. The "readiness model" that supports community integration through gradual skill development in segregated settings has all but been abandoned in favor of a "zero reject" paradigm that promotes inclusion for all, regardless of the severity of disability, with whatever supports are needed to insure success. The Commonwealth is home to exemplars of full inclusion--agencies, schools, and communities that support persons who have attained extraordinary levels of inclusion. Yet the difficulty of implementing this model is exemplified by the numbers of citizens who continue to live, work, and go to school in segregated settings.

The Governor's Commission on Mental Retardation is required to hold at least two public hearings annually. One purpose of these hearings, as described in the Commission's Executive Order, is "to highlight the extent to which the private sector and the community at large provide opportunities for persons with mental retardation." Accordingly, the sixth and final public hearing of the first term of the Commission was devoted to an examination of strategies that promote community inclusion.

The hearing was held on September 24, 1996, at Worcester State College. Both oral and written testimony was solicited from individuals who have mental retardation, their families, providers, advocates, and state agency officials across the state. Fifty-five persons attended the hearing, 24 submitted oral testimony and 22 submitted written testimony.

This report highlights the complexities surrounding inclusion in three sections:

- A brief history and overview of the critical issues in the field.
- Specific strategies to promote inclusion based on the testimony from the public hearing.
- Recommendations for future activity.

A Word about Words: the Definition of Inclusion

The term "inclusion" is rooted in special education. Virginia Roach, in her article "Supporting inclusion--beyond the rhetoric" (1995), suggests that school-based inclusion "can be defined as the practice of serving a student with a full range of abilities and disabilities in the general education classroom--with appropriate in-class supports" (p. 295). Although she notes that inclusion can mean different things in different states and even in individual schools, Roach cautions that inclusion is more than a different name for "mainstreaming." Within the "mainstreaming" paradigm, a student leaves his or her regular classroom for special education instruction--often for most of the day. Until a student can participate in regular activities without support, no increase of time in the regular classroom is recommended. In distinct contrast, the inclusion model starts with the assumption that all children are to be part of the regular classroom with individualized supports brought to children with specific needs.

In the same way that classroom inclusion is different from mainstreaming, so too, is community inclusion or membership different from community adjustment, community presence, and community participation. William Kiernan, Executive Director of the Institute for Community Inclusion, writes, "*Inclusion is:*

- *not being in a community but rather being part of a community fabric;*
- *not needing to be determined to be eligible but presumed that all settings, supports and services are available;*
- *not defined as 'all but' rather as everyone;*
- *not setting up special centers but rather recognizing the variety of needs and responding to those needs in the typical community settings; and*
- *not focusing on fixing the individual but altering settings to meet individual preference and interest.*

Inclusion means being an integral part of and having control over those events, services, and supports that will influence one's life."

For the purposes of this report, "community inclusion" and "membership" will be used interchangeably. "Community presence" and "community participation" will refer to activities that help promote inclusion and community membership.

Overview

A. History

For most of the 20th century, families who needed help caring for persons with mental retardation had but one choice--placement in a large state-funded institution. In his history of mental retardation services entitled Inventing the Feeble Mind, James W. Trent notes that between 1950 and 1970, more public facilities for persons with mental retardation were built, refurbished, and expanded than during any other time in U.S. history. Between 1946 and 1967, the population of the institutions also grew from 116,828 to 193,188, an increase of 65% and nearly twice the rate of increase for the general population (p. 251). While utilization was at an all time high, quality of care was deplorable. Federal dollars were available to build institutions, but there was no federal support to pay for their upkeep or for staff. It was not until 1971 when Congress, hearing the pleas of family members and other advocates, permitted federal reimbursement to intermediate care facilities for persons with mental retardation (ICFs-MR). The conversion of state-run institutions to ICFs-MR coupled with multiple state consent decrees led to dramatic improvements in staffing, environmental conditions, and protection of human rights.

The model of quality for the Title XIX regulations that monitor the ICFs-MR promoted highly specialized professional therapies and treatment. Good care was synonymous with specialized, segregated care. Advocacy for school-age children with mental retardation also reinforced the need for specialized care apart from "normal" children. Through the advocacy of entities such as the National Association for Retarded Children, founded in 1950, special education classes increased by 500% between 1948 and 1958. Still, in 1966, 50% of all children with mental retardation had no access to education, and 50% of all local school systems had no special education classes (p. 242). In the effort to demand more services for their children, parents emphasized the need for highly specialized services. Access to regular classroom education diminished. By 1963, less than 10% of public school students who had mental retardation spent any time in regular classes. Trent concludes: "Thus in their struggle to expand community services to supplement state institutions, parents reinforced a vision of special education that went back to the beginning of the century....Special education children in local schools would learn together, segregated from their chronological peers" (p. 243).

P.L. 94-142, the Education for All Handicapped Children Act of 1975, established the right to free and appropriate public education for all children. Its mandate to provide education for all children--regardless of their level of disability--signalled a profound change in the disability movement as services were no longer conceived as a form of charity but now as a civil right.

Beginning in the 1970s and extending through the 1980s, tens of thousands of citizens left the institutions for community services. Early group homes relied on concepts such as "community adjustment" and "community awareness." Staff charted the number of times a client "used" the community by shopping for food or personal items. This type of physical integration into the community was accomplished fairly quickly, but it was not accompanied by a deeper, more fundamental sense of community membership. Warnings about the limitations of physical inclusion sounded early. Wolfensberger noted in 1972 that, "Ultimately, integration is meaningful if it is social integration, i.e. if it involves social interaction and acceptance and not merely physical presence" (cited in Bradley, p. 12).

Over the past decade, numerous studies revealed that most persons with mental retardation lead socially isolated lives (Bogdan & Taylor, 1987; Lakin, Burwell, Hayden, & Jackson, 1992). Activities in the community were found to be fairly frequent, but these were usually done in groups with other persons with mental retardation (Rosen & Burchard, 1990). Friendships between persons with and without disabilities were rare, and the primary relationships for persons living away from home were with housemates and paid staff--staff whose low wages incurred large levels of turnover (Schalock & Lilley, 1986).

Nor was this lack of community membership apparent only in persons who had left institutions; those growing up in family homes were isolated as well. A call for a "paradigm shift" developed out of the realization that isolation was an endemic experience for most persons with mental retardation. One example of this shift came in 1992, when the American Association on Mental Retardation (AAMR) revised its definition of mental retardation: "Mental retardation, as a diagnosis, has evolved from a description of individual functioning independent of setting to a description of individual functioning that can only be made within the context of community life" (AAMR, 1992, p. 101).

Federal legislation supported inclusive community-based services. The 1992 Rehabilitation Act eliminated the "employability" standard, as all citizens were now presumed employable. The revision of the special education act (also of 1993), called the Individuals with Disabilities Education Act (IDEA), mandated access to regular classrooms. The implementation of the Federal Medicaid Home and Community-Based Waiver also transformed service delivery. Established in 1981, the program was specifically designed to provide an alternative to institutionally-based care, and by 1992, national expenditures for community-based services surpassed funding for large facilities.

It is clear that both philosophy and policy has changed--there is a growing consensus that community membership must be a priority for helping persons with mental retardation lead high quality lives. Yet practice continues to fall short. William Kiernan noted in his written testimony, *"The statutory table has been set yet we continue to struggle with the menu for the banquet."* Indeed, a cursory review of the current situation is sobering:

- Across the nation in 1992, 47.5% of citizens with mental retardation receiving residential services lived in 16+ bed settings or in nursing homes (Braddock, Hemp, Bachelder, & Fujiura, 1995).
- A national survey of day and work services found that in 1990, 81% of all those receiving services did so in segregated settings--both in sheltered work and non-work based day services (McGaughey, Lynch, Morganstern, Kiernan, & Schalock, 1991).
- In 1992-93, more than 60% of all children between the ages of 6 and 21 who received special education services were not included in regular classroom settings (U.S. Department of Education, 1995, cited in Roach, 1995).
- Two surveys of adults with mental retardation who lived in community settings found that only 3% and 4% of close friends were community members. A majority of respondents did not have a single friend without a disability who was a member of the community (Abery, Thurlow, Johnson, & Bruininks, 1990; Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989).
- In Massachusetts, one third of persons with mental retardation who receive residential services do so either in ICF-MR facilities or in community-based nursing homes ('95 DMR Annual Report; Braddock, Hemp, Bachelder & Fujiura, 1995). 75% of persons who receive day services attend segregated settings: day habilitation and adult day health programs and sheltered workshops ('95 DMR Annual Report and oral communication with DMA). For persons who receive special education services, only 15% are fully included in their regular classes with modifications and supports (Statewide Prototype Distribution, DOE, 1995).

B. Benefits and obstacles to inclusion

Benefits

Over the past 15 years, multiple studies, including one by the National Academy of Sciences, revealed flaws in both the assessment of children with special needs and in the ways placement strategies for these children were developed (Staub & Peck, 1995). This evidence prompted further examination of the impact of segregation on children with special needs. These studies conclude that segregation of children with special needs is "actually deleterious to their academic performance and social adjustment." (Baker, Wang, & Walberg, 1995). There is also evidence that the amount of time children with disabilities spend with non-disabled peers positively impacts the acquisition of communication and social skills, achievement of educational objectives, and parental expectations of their children's future. In their review of this research, Karagiannis, Stainback, and Stainback (1995) summarized: "In general, the more time students with disabilities spend in inclusive settings, the better they do educationally, socially, and occupationally."

Studies of the benefits of full inclusion in the general classroom (versus the amount of time spent with peers) are much more limited, yet also suggest positive outcomes. In its review of the research, the National Center on Educational Restructuring and Inclusion reported that children with mild, moderate, and severe disabilities in general education settings were found to do as well or better than those in more segregated settings, especially in *social competence*. "The research and evaluation data on inclusion indicate a strong trend toward improved student outcomes (academic, behavior, and social) for both special and general education students" (PCMR, 1995).

While there is an emerging consensus that inclusion benefits children with special needs, other stakeholders including parents, teachers, and school administrators have expressed concern over the impact of inclusion on children without disabilities. These concerns include the allocation of teacher time, diminished academic challenge due to curriculum modification, and the potential increase of maladaptive behavior among children without disabilities following exposure to children with disabilities. Research on the impact of inclusion on students without disabilities is limited, but several studies found that there is no deceleration in academic progress for children without disabilities in inclusive classrooms (Odom, Deklyen, & Jenkins, 1984; Brinker & Thorpe, 1984). One

study of six randomly selected non-disabled students in an inclusive classroom found that the presence of students with disabilities had no effect on the amount of time teachers spent with the non-disabled students. Nor were interruptions to instruction significantly different in inclusive and non-inclusive classrooms. Surveys of parents and teachers with direct experience with inclusive settings have also noted benefits for students without disabilities--particularly in the areas of social competence and self concept as well as reduced fear of persons with disabilities. While these limited studies suggest benefits, cautionary notes have also sounded. Michael F. Giangreco of the University of Vermont wrote in his testimony: *"Some school districts are placing students in general education classes without appropriate individualization and support--though they may call this 'inclusion,' I suggest to you that it is not. No one wants students 'dumped' into general education, but as my friend and colleague, Michael Hock, likes to tell people regarding inclusion, 'Doing it wrong doesn't make it wrong.'"* In a similar vein, Karagiannis, Stainback, and Stainback suggest "Genuine inclusion does not mean dumping students with disabilities into general education classes without support of teachers or students. In other words, the primary goal of inclusive schooling is not to save money: it is to adequately serve all students."

The promotion of community inclusion for adults with mental retardation has not been accompanied by research regarding its benefits. There is, however, substantive evidence that for adults in general both the quality and quantity of one's social network is linked to depression, psychological distress, and job dissatisfaction. Social connectedness is also a key factor in stress reduction, effective coping, and enhanced "mental well-being" (Abery & Fahnestock, 1995).

Obstacles

Both the literature and the testimony reveal persistent obstacles to inclusion. These difficulties can be summarized in four points:

- There is limited attention paid to the development of skills that would promote inclusion.
- Adults who have mental retardation lack the economic and social resources to lead active lives in the community.
- Society remains reluctant to include persons with mental retardation and other disabilities.
- Funding sources continue to pay for services that are located in restrictive settings.

Lack of emphasis on skill development

Community isolation and restricted social relationships have long been

attributed to both cognitive and adaptive skill deficits. Research confirms that higher levels of adaptive skills and less cognitive impairment are associated with increased social inclusion (Hill, Lakin, Bruininks, Amado, Anderson, & Copher, 1989). It is also commonly acknowledged that job loss among adults with mental retardation is frequently attributed to social skill rather than work skill deficits (Greenspan & Shoultz 1981; Hanley-Maxwell, Rusch, Chadsey-Rusch, & Renzaglia, 1986).

Lack of economic and social resources

At the public hearing, Julie Burt, Director of Support Services for the Greater Waltham Arc, noted that many of the recipients of her agency's services are unable to participate in community activities because of financial and transportation restrictions. She reported that many cannot afford the cost of a \$7 movie or the cost of carfare to attend an activity. Nor were her clients able to access public transportation. Family members, often aging and financially stretched, were unable to provide additional financial support. The literature confirms the need for concrete support including access to transportation and money to pay for social events as well as to information about community activities (Schleien & Ray, 1988).

Social stigma

Abery and Fahnestock (1994) note that society's negative attitudes towards persons with mental retardation and other disabilities significantly impact social inclusion. They report that decades of research on "peer acceptance" confirm that persons without disabilities have more negative attitudes toward those with disabilities. People with mental retardation are perceived as having less favorable social behaviors and as less physically attractive. Abery and Fahnestock suggest that younger children have fewer negative opinions about persons with disabilities. They cite a 1987 survey by Meyer and Putnam who report that while 40% of a sample of elementary school students indicated that they would voluntarily interact with a peer with a disability, only 15% of a sample of high school students indicated that they would befriend a person with a disability.

Current funding is spent on restrictive settings

Payment systems have a powerful influence over the scope, nature, and quality of services. Because they fund programs rather than individualized services, current funding practices create fiscal incentives for state agencies and service providers to congregate and segregate individuals with disabilities.

It is clear from both the literature and the testimony that community inclusion is a viable prospect for citizens who have mental retardation. While there is an ever growing recognition that persons with mental retardation are capable of community membership and benefit from inclusion, its full implementation continues to be an unmet challenge.

Strategies for Promoting Inclusion: A Review of the Testimony

Throughout the hearing, 24 providers, advocates, and family members gave testimony on strategies to enhance inclusion. Written testimony was also received from 22 persons. Collectively, the recommendations are to:

- Enhance collaboration among all stakeholders.
- Re-direct funding to services that promote inclusion.
- Educate the community.

A. *Enhance collaboration among all stakeholders*

Throughout the public hearing, testifiers emphasized that to fully include a child with special needs in a regular classroom, all members of the school community must be considered part of the team. Doris Goldthwaite, Director of Student Services for the Wayland Public Schools, noted *"It is so important that each person who touches the child's life have an attitude of reaching out to that child rather than just responding to the letter of the law...everyone from secretaries to bus drivers to coaches to cafeteria workers."* Bill Henderson, Principal of the Patrick O'Hearn School in Boston, concurred, suggesting that *"special education and regular education can no longer be separate disciplines.... It is the entire community, the custodian, the secretary, it is everyone."*

Supporting teachers, parents, students

Much of the literature on supporting classroom inclusion emphasizes the need for **teachers** to be granted time to meet with one another and to observe more experienced teachers at work in the classroom (Roach, 1995; Giangreco, 1993; Baumgart & Giangreco, 1996). Michael Giangreco, who submitted several of his articles as written testimony, noted *"Teachers who found support personnel helpful cited four facilitating practices: shared framework and goals, physical presence, validation of the teacher's contribution, and teamwork. Teachers reported that the physical presence of another person on whom they could rely was helpful; this minimized the feeling of being totally alone or totally responsible"* (1993). These sentiments were also reflected by oral testimony. Jean Bean, Director of Special Education and Student Services for the Northboro-Southboro school system, reflected that *"classroom teachers need less training [in inclusion] than they think they need....[Regular education teachers] simply need to have the time to sit down*

with their colleagues in special education and parents [to] brainstorm in planning solutions." Bill Henderson offered a similar strategy: "Kindergarten teachers [need to know] what we are doing with three and four year olds...and middle school teachers seeing what they're doing with fifth grade...not just having kids show up on the first day."

One example of training teachers through collaboration was presented by Geri Bargar of the Greater Plymouth Arc. Her written testimony describes the Teacher Support Network, *"a training network to meet the educational, training and support needs of both special education teachers, general education teachers, administrators and therapists working in classrooms where students with disabilities are included with their non-disabled peers. The main goal of this network is for teachers to share with each other their 'recipes for success.'"* Each presenter is asked to teach a new skill that can be immediately put to use. In the 1995-96 school year, 106 teachers from ten towns participated in at least one of the six workshops.

Parents often face a lonely journey when pursuing an inclusive education for their children. Judith Rhome of Sudbury suggests that when parents are enrolling their child in an inclusive class, they should receive *"the names of parents of age appropriate children who would be supportive and welcoming."* Parent collaboration was also a focus of Madeline Howard-Rutkowski's testimony. Her DMR-funded agency, Fidelity House, offers support to parents through a project that uses *"an education series to broaden parents' understanding of the various issues that are associated with making inclusion successful."* An unexpected outcome of the parent training was the creation of a monthly support group where parents, some with children who have special needs, meet to share common concerns.

Students also need support and education around disabilities. Ms. Howard-Rutkowski notes in her written testimony that when *"children are able to accept differences as children, then they are more likely to accept and offer friendships as adults."* Doris Goldthwaite, Director of Student Support Services in the Wayland Public Schools, suggested that school age children be provided opportunities to learn about disabilities and to ask questions: *"It is pretty easy when you start with little kids because their natural openness is very easy to accommodate to whatever the person's difference is....The peer group is very important in terms of*

maintaining the acceptance [of children with special needs]....We find that as kids grow, and their own developmental level changes, we need to have on-going discussions with kids, again especially in middle school and high school levels to answer the questions that come up."

Focus on: Massachusetts Department of Education Inclusion Mentors
--

<p>The Massachusetts DOE has established nine inclusion mentor school districts: Abington, Barnstable, Danvers, West Springfield, Northboro/Southboro, Scituate, Union #28 (Shutesbury), Wayland and Holliston. At the culmination of a three year federal grant, the Department is hoping to have 30 new communities in the Commonwealth practicing inclusive education. In 1995, designated schools within each of the mentoring districts received training, time off to observe inclusive schools, and in-classroom support. In some of these schools, regular education and special education teachers have time together to plan and modify curricula, and they co-teach all children. Each mentor school is to designate two neighboring districts and three schools within each district. Mentor schools then provide the training for these new schools.</p>

B. Redirect current funding

Many testifiers urged the Commonwealth to examine and restructure payment systems to support strategies that emphasize inclusion. William Kiernan suggests: *"Have resources redirected to support the provision of supports in community settings and not segregated settings."* In his written testimony, Jeffrey Strully, Executive Director of Jay Nolan Community Services in Chatsworth, CA, notes that inclusion does not cost more than traditional services. *"We basically used the same level of funding which we had previously received for our group homes and our day behavior management programs to support people who moved into their own places and/or do things in the day that is personalized. Supporting people to live valued lives in the community does not cost more money than congregating and segregating people in the community."*

Hearing participants applauded the development of the DOE/DMR Interagency Agreement that through a collaborative effort assumes responsibility for education and other support services within the home district. This project has successfully demonstrated that *"cost effective and least restrictive services can be developed to return students with difficult educational and support needs to local schools, and to a home or an apartment or group home setting."* As of this date, 80 students participate in the project. Of this number, 79 individuals have returned to their communities to more inclusive educational and residential settings. *"This project has been highly successful because it has stressed inclusion from the start,"* noted Ernie Van Deusen, Director of Family Support, Department of Mental Retardation.

Focus on: The DMR-DOE Interagency Agreement

- provides flexibility in the delivery of services to young people who require intensive and coordinated special education services and residential support;
- develops a mechanism to pay for and deliver family support services and/or community-based residential services in a less restrictive setting at an equal or lower cost than services provided in residential special education schools;
- expands public school opportunities for young people who meet DMR's eligibility criteria by returning individuals from residential special education schools to home communities and providing the necessary supports that enable them to remain there.

Individualize services

Families and human service agencies have pointed to the need to be creative in the development, design, and funding of support. Procurement requirements need to reflect a more individualized and flexible approach. Several examples were presented during the hearing that describe the benefits of individualized funding: *"Flexible funding was used by a family to allow a young girl with severe physical disabilities to participate in camping trips with her local scout troop--the funding paid for the cost of a respite care worker to assist her with personal needs and the added expense of transportation,"* stated Lesley Kinney, Associate Director of the Franklin County Association for Retarded Citizens.

The Greater Boston Arc (GBArc) submitted information in their written testimony about its program called Kids of All Learning Abilities (KOALA). KOALA's goal is to *"to help Boston area families locate integrated recreational opportunities for their children with special needs."* To accomplish this, a KOALA integration specialist visits each child at school to determine ability level, as well as strengths and area of need. *"The integration specialist then arranges an initial meeting at the desired center between parent, child, and program staff. The child's teacher, parents and program staff work together with the integration specialist to develop individual guidelines for the child."* The integration specialist then assists with the children's transition into the program and provides on-going consultation and support to the participating centers. Children participate in such activities as after school and summer camps at neighborhood YMCA/YWCAs, Girls' and Boys' Clubs, religious organizations and schools.

Pam Bliss, from Beta Community Services, provided an example of using current resources in an individualized manner. Her written testimony describes her work *"primarily with a core group of six consumers to intensely connect them to the community via service and interest groups, church and local activities, and their surrounding neighborhoods."* She holds planning sessions with the individual, family members, and friends to gather information on past history, interests, and dreams. Based on that information, she seeks out the appropriate groups within the community. Both staff and volunteers provide support to maintain those connections.

Expand resources

Several testifiers noted the benefit of expanding resources to promote inclusion. *"We should take a look at community inclusion in terms of innovation grants, in terms of training council grants, in terms of the new dollars that we got in certain areas,"* suggested Diane Enochs, Region II Director, Department of Mental Retardation.

C. Educate the community

Both oral and written testimony highlighted the need for community education. Many testifiers agreed with Madeline Howard-Rutkowski that in order for inclusion to be successful, the community needs to be educated to the point that they *"see the person first and not the disability."* She suggested that, *"The challenge in getting community groups to open their doors lies in the lack of familiarity with people who have mental retardation."* Albert Bleau, Executive Director of the Greater Lynn Mental Health and Retardation Association, further recommended that funding be allocated to educate the community through the development of anti-stigma committees--comprised of consumers, family members, and providers--to foster communities to work together; develop videos; conduct outreach to schools and develop a statewide plan for promotion and public service announcements.

Testimony from the Hearing

Diane Enochs, Director for Region II, Department of Mental Retardation, recounted in her oral testimony an example of spontaneous community education:

"A group residence was struggling with the issues of community membership. The group home happened to be located in a neighborhood that was focusing on revitalization and beautification. A neighbor came to the door to enlist the help of the residents in the neighborhood project. But when he found out that this was a home where people with mental retardation lived, he apologetically left and confided that he knew that there was nothing the group home residents could help with. The resourceful group home manager, however, begged to differ and indicated that the people living in the group home would assist in any way that they could. It turned out that the group home residents could easily hand out flyers to other neighbors. In fact, this project enabled the group home residents to get to know more of the people living in the neighborhood where they had been living quietly for the past three years. "

Testifiers repeatedly mentioned the need for passion, vision, and hard work

in order for the rhetoric of inclusion to become a reality. By allowing teachers and others to have time to collaborate with one another, through the re-allocation of current resources in ways which fund inclusion, and through community education, enhanced inclusion is possible for citizens who have mental retardation.

Recommendations

Throughout the public hearing, there was universal affirmation that community inclusion benefits both persons with mental retardation and the community as a whole. The Governor's Commission on Mental Retardation commends the extraordinary efforts of family members, self advocates, community groups, providers, school systems, and state agencies, including the Departments of Mental Retardation and Education, to promote full community inclusion for citizens who have mental retardation. As the public hearing revealed, inclusion remains a goal rather than a reality. The Governor's Commission on Mental Retardation calls on all parties to renew their commitment to the implementation of full inclusion and makes the following recommendations:

1. Re-direct resources to increase opportunities for inclusion.

"...we must re-direct resources from segregated to integrated settings. We must be more creative about the options [currently available] in the community, we must have strategies to access existing services...." William Kiernan, Executive Director, Institute for Community Inclusion

Historically, state funding provisions, reimbursement formulas, and financial practices have created fiscal incentives for state agencies and service providers to congregate and segregate individuals with disabilities. The Commission commends the development of the DOE/DMR Interagency Agreement that promotes a collaborative effort to assume responsibility for educational and other support services within the home district. This project recognizes the importance of a funding formula that allows families and schools to work together to assemble the needed supports to maintain an inclusive community that benefits all children. The Commission recommends an expansion of this project first by fully funding the agreement. Then, in order to minimize unnecessary out-of-home placements, resources currently allocated to DOE for all DMR-eligible children and their families should be re-directed to DMR. This would be both a cost-effective and quality enhancing utilization of existing funds.

Recognizing that funding streams are the most potent tools to enact change, fiscal incentives should be embedded in all of the state's procurement practices. Request for Proposals (RFPs) should include priority preference for those individuals and programs that incorporate and promote inclusion, especially in day and work services.

Families and human service agencies have pointed out the need to be more creative in the development and design of support options and the payment for such options. Current prohibitions need to be examined and altered to permit more flexibility, with the goal being to fund individual needs rather than program slots.

The DMR document entitled "Supporting People's Homes and Lives" and the Consumer Empowered Proposal Initiative clearly reflect a renewed emphasis on and commitment to the concept of inclusion through enhanced self-determination. We encourage and support the further expansion of these activities.

2. Promote inclusion in schools through increased collaboration.

"The education community needs to take joint responsibility for the individual learning needs of all children--not segregated responsibilities for separate children." --Judith Rhome, Parent

Throughout the hearing, ample evidence was provided to demonstrate the benefits of combining special education and regular education teaching practices in inclusive settings and utilizing team teaching and multi-sensory methodologies--with shared resources, therapeutic expertise in the classroom, and peer supports. The Commission recommends that these techniques be expanded throughout public education.

The Governor's Commission applauds the efforts of the Massachusetts Department of Education to promote classroom inclusion through the implementation of Mentoring Grants which fund school districts to become fully inclusive and then serve as mentors to other districts. The Commission recommends that this program expand significantly so that by the year 2005, all school districts are practicing inclusion.

The Commission recognizes that the "journey to inclusion" can be a lonely one for families and students. Opportunities for parents to collaborate and share successes and trials, such as the groups sponsored by Fidelity House and the Lawrence and Franklin County Arcs, should be available to all families.

3. Promote inclusion through the sharing of best practices.

The Governor's Commission on Mental Retardation recognizes from the testimony that information sharing, discussion of strategies, and showcasing of "best practices" are essential components to enhancing inclusion. The Commission recommends that multiple forums be established so that all stakeholders--families, self advocates, providers, educators, community groups, recreational groups, business groups, etc.--have the opportunity to share information and strategies that support and facilitate inclusion.

References

- AAMR, Mental Retardation: Definition, Classification, and Systems of Supports. (1992). Washington, D.C.: AAMR
- Abery, B.H. & Fahnestock, M. (1994) Enhancing the social Inclusion of Persons with Developmental Disabilities. In eds Hayden M.F. & Abery B.H. Challenges for a Service System in Transition: Ensuring Quality Community Experiences for Person with Developmental Disabilities. Baltimore: Paul H. Brookes Co.
- Blaney, B.C. & Freud, E.L. (1994) Trying to Play Together: Competing Paradigms in 'Approaches to Inclusion Through Recreation and Leisure. In Creating Individual Supports for People with Developmental Disabilities: A Mandate for Change at Many Levels, ed V. J. Bradley, J.W. Ashbaugh, B.C. Blaney, 3-10, Baltimore: Paul H. Brooks, Co.
- Fujiura, G.T. & Braddock, D. (1992) Fiscal and Demographic Trends in Mental Retardation Services: The Emergence of the Family. In L. Rowitz (Ed.), Mental Retardation in the Year 2000. New York: Springer-Verlag.
- Giangreco, M.F., Baumgart, D.M.J., & Doyle, M.B. (199?), How Inclusion Can Facilitate Teaching and Learning. *Intervention in School and Clinic* 273-
- Jorgensen, C.M. (1992) Natural Supports in Inclusive Schools: Curricular and Teaching Strategies. In ed. Jan Nisbet, Natural Supports in School, at Work, and in the Community for People with Severe Disabilities. Baltimore: Paul H. Brookes Publishing Co.
- Nisbet, Jan, Jorgensen, C., Powers, S. (1994) System Change Directed at Inclusive Education. In Creating Individual Supports for People with Developmental Disabilities: A Mandate for Change at Many Levels, ed V. J. Bradley, J.W. Ashbaugh, B.C. Blaney, 3-10, Baltimore: Paul H. Brooks, Co.
- Roach, V., Supporting Inclusion, Beyond the Rhetoric. *Phil Delta Kappan*, December 1995, 288-291.
- Smith, G.A. & Gettings, R.M. (1994), The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community. Alexandria, VA: NASDDDS, Inc.
- Strully, J.L. & Strully C.F. (1992). The Struggle Toward Inclusion and the Fulfillment of Friendship. In ed. Jan Nisbet, Natural Supports in School, at Work, and in the Community for People with Severe Disabilities. Baltimore: Paul H. Brookes Publishing Co.

Trent, J. W. (1994). Inventing the Feeble Mind: A History of Mental Retardation in the United States. Berkeley and Los Angeles: University of California Press, Ltd.

Thousand, J.S. & Villa, R.A. (1995) Inclusion--Alive and Well in the Green Mountain State. Phil Delta Kappan, December 1995, 288-291

Trent, J.W. (1994) Inventing the Feeble Mind. Berkeley and Los Angeles: University of California Press.